DOCUMENT RESUME

ED 145 614 **EC 102 556**

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TITLE	Why Do Families Need Respite Care? Building a Support System.
INSTITUTION	Montgomery County Association for Retarded Citizens, Silver Spring, Md.
PUB DATE	Jun 77
NOTE	18p.
EDRS PRICE	MF-$0.83 HC-$1.67 Plus Postage.
DESCRIPTORS	*Community Resources; Community Services; Exceptional Child Services; *Family Attitudes; Family Counseling; *Handicapped Children; *Respite Care

ABSTRACT

The role of support services in providing respite care for families of handicapped children is discussed. Areas in which families need assistance are explained to include basic tasks of family living and crisis management, while sources of support are seen to include role models, close friends and information agents. Exercises are described to assess personal support systems. (CL)

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WHY DO FAMILIES NEED RESPITE CARE?

BUILDING A SUPPORT SYSTEM

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funded by

The Maryland State Planning Council
on Developmental Disabilities

through a grant to

Family and Community Services
Montgomery Co. Association for Retarded Citizens
11212 Norris Drive
Silver Spring, Maryland 20902

June, 1977

RESPITE CARE.....WHAT IS IT?

Respite care -- short-term, temporary care of a family member with a disability

Respite care -- an interval of time that allows a family relief from its daily routine

Respite care -- a vital supportive service; an aid in keeping families together a well-deserved necessity

If statistics can be trusted, one out of every ten families has a physically handicapped, mentally retarded, or emotionally disturbed member with special needs. In most of these families, the handicapped child or adult places an extra burden of care on mothers, fathers, brothers, and sisters.

When a child, because of mental or physical limitations, is unable to set up activities and provide amusement for himself,

When friends live miles away rather than around the corner because they go to special schools,

When siblings have -- as they should -- their own friends and activities to engage them,

the unending responsibility for care, encouragement, training, and daily life routines all falls on parents already carrying heavy burdens and often lacking the time, the energy, and the inclination to set up supportive systems not easily accessible. With little relief from daily responsibilities, frustrations, feelings of isolation, physical and psychic fatigue steadily mount.

But relief from the daily routine is vital for everyone to maintain positive mental health: all people need a chance for renewal, a time for being alone to regain perspective, composure, and humor, and -- in the particular case of families with disabled members -- a chance for husband and wife to know each other as people and not just as parents of a handicapped child. Revitalization is imperative, "normalization" for parents and siblings of the handicapped is a necessity.

FAMILIES NEED .....

Rest

Relief

As normal a way of life as possible

The freedom to socialize

A time to relax

And what of the child with a handicap?

Learning to get along with a variety of adults is an important part of <u>any</u> child's upbringing. Often the child with a disability has fewer contacts outside of his home and is far more isolated than his nonhandicapped peers. Opportunities, therefore, must be created for him to learn to know and trust others. The child with a handicap is being denied an important and essential growth experience if his family does not allow him the chance to be with other competent, caring people.

THE CHILD NEEDS .....

A chance to grow

An opportunity to learn

A means of establishing trust

An identity beyond his immediate family

Respite care cannot be considered a luxury; it is a necessity if families are to stay together and function well together. Parents deserve relief from their daily responsibilities; their handicapped children must learn to know and trust people outside their immediate families. The long range effects of this supportive service can only produce happier, freer, and less anxiety-ridden people.

REMEMBER!

TIME AWAY FROM ONGOING RESPONSIBILITIES IS ESSENTIAL FOR PARENTS

CHILDREN NEED EXPERIENCE IN RELATING TO OTHER ADULTS

WHY DO FAMILIES NEED RESPITE CARE?

Two thoughts, both simple and obvious, have been the stimulus for what follows. First: families have, as one of their primary reasons for being, the enhancement of the welfare of their members. Second: families can only serve that function when they creatively draw upon the support of a wide range of individuals, groups, and organizations.

Many families, and individual members of families, have made a virtue of "going it on their own". Independence and autonomy and self-reliance are values which are honored, even in times of great stress and difficulty. The use of outside support is seen as a weakness or experienced as a failure. This model seems to serve some families well, while for other families it leads to self-limiting, self-defeating, and self-destructive ends.

Families in which there are members with developmental disabilities often find themselves in the position of not being able to provide the necessary nurturance for each other and yet not knowing how or where to turn for support outside the family. Thinking through their own network or system of supportive persons and organizations seems an extremely complex task which most families never sit down and do. Our goal is to offer families and individuals a way of thinking through what help they have, what help they need, and what respite care can do for them.

WHAT MAKES UP A SUPPORT SYSTEM?

The very words, "support system", may be unfamiliar or conjure up images ranging from a building foundation to an oxygen supply. It is used here to mean a network of individuals, groups, and organizations with the potential of supplying resources to a

person or family. It might be thought of as one's own private "yellow pages", where there is the potential for a wide range of contacts. It may include individuals to whom one is intimately and deeply attached or persons as distant and impersonal as a delivery service. The people may vary from being warm and loving to provocative and challenging. The relationships can range from formal and expert to simply companionable.

It is rarely a system in which all the individuals know each other, even though they are known to the person or family to whom they provide support. And the motivations of people to be supportive may range from purely monetary to completely altruistic. Most importantly, the system is generally known only to the individual involved and even then the person or family may never have done any systematic identification of people who are or might be available.

In short, it is other people who make up our support systems -- other people who act on their own, or as part of groups, businesses, or organizations. What they have to offer varies tremendously, and it is our skill in building relationships with them that can greatly determine whether or not they will "be there for us" when we need them. Moreover, skillful use of supportive resources is not without traps and pitfalls, and the development and maintenance of such a system requires a good deal of time and energy. And there is always the possibility that it may not work well or even cause us greater difficulty. It is no guaranteed panacea for any of our needs. It represents possibilities for assistance, for supplying extra energy, or for helping us achieve a wide range of goals. The task, then, is to increase the possibility that we will have access to those resources without having to pay a price that is either unrealistic or unreasonable. And, perhaps most important, we must learn to use supports that leave us stronger as individuals and families rather than weaker and more dependent.

WHAT DO FAMILIES NEED SUPPORT SYSTEMS FOR?

Obviously, there are times when a family does beautifully at providing for the basic needs of its members and there are times when it may falter and fail. Some of the times when assistance is needed occur when there are problems in the following areas:

A. Carrying out the basic tasks of family living. Small or large, families seem to have a bottomless pit of "things to do" just to keep things moving on an even keel. Providing and keeping up living space, shopping and preparing meals, keeping cars and appliances in working order, and getting family members to and from places outside the home are a few examples.

B. Managing crises. In addition to the routine tasks of running and maintaining a household, every family faces its share of unexpected, out-of-the-routine crises which demand special attention and resources. Who knows why the water heater bursts on the day the car won't run on the day that grandmother arrives in a wheelchair? More seriously, accidents, deaths, fires, blizzards, and crime are some of the crises with which we occasionally must cope. For some families and individuals, crises are few and far between. But for many, the occurence of a crisis becomes almost an accepted part of daily living. And when there is not a crisis, it is possible to feel equal tension -- wondering when the next calamity will hit.

C. Maintaining one's skills and competency. This is an especially important area for adults who have had a chance to beomce competent and resourceful and then fail to find the opportunities for keeping these competencies sharp and well-developed. Competencies may range from skills in enjoying recreational activities to performing complicated tasks

in a work setting. In families where there is high stress, it is all too frequent that members lose their interest in participating in activities outside of their own homes or, more importantly, forget that they have the capacity to learn and the ability to cope with new and challenging situations. Having support in order to maintain one's talents can be a critical part of keeping a sense of self-esteem and mastery.

D. Stretching, growing, and developing new abilities. Different kinds of support may be needed in helping family members, particularly parents, develop new aspects of themselves rather than fall into the trap of using only those skills which were learned in the past. Many stretching and growthful activities seem threatening because of fear of failing or looking foolish during those uncomfortable bumbles which accompany experiences with the unfamiliar. The feeling of "I could never do that!" can easily creep into the picture we have of ourselves and become a self-fulfilling prophecy.

In summary, individuals and families need supportive persons, services, and organizations to call on in the course of ordinary living. It can be strengthening to know that you can call upon these resources if and when you need them. It is important to recognize that needs for support range from survival of a crisis to developing completely new and different skills. Just keeping the show going and maintaining oneself in condition so that already developed skills are useable may also require support. Well-developed and readily available support systems can make the difference for a family between a life of bare subsistance and a life with rich opportunities for growth, achievement, and pleasure.

WHAT ARE SUPPORT SYSTEMS LIKE FOR YOU AS AN INDIVIDUAL?

There seems to be no limit to the variations in the way different people would describe their support systems. Starting with the simplest scheme, a surprising number of people feel that there is no support system they feel they can rely on outside of themselves or the immediate members of their family. Although this notion rarely turns out to be the case, the important point is that they feel that it is the case and therefore act as if it were true. This leads inevitably to a sense of isolation -- I am the only one I can count on, and perhaps only on my best days. It is experienced as isolation from emotional support, isolation from people who share the same kinds of concerns, isolation from people who have needed resources, isolation from individuals who can challenge and teach, and isolation from people who can help to locate where to go for assistance.

Individuals who can identify no support system frequently find themselves drawing in more and more, engaging in less contact with other members of their family, neighborhood, community, or the organizations and professionals they have used in the past. This tendency to withdraw becomes part of a downward spiral which makes coping difficult, if not altogether impossible.

At the other extreme, we find people who seem to have an endless supply of contacts they can call on. Their conception of what can be potentially supportive to them seems boundless and they attribute human qualities to their pets, bathtubs, automobiles, and furniture as well as to the actual helpers they can muster for any given task. If they face a dilemma, it is for them more the problem of choice than availability. The one danger they experience in always using other persons for support may be in never testing their own capacity for self-reliance.

As indicated earlier, there are many different ways in which people can be supportive. Some of the types of support which can be of assistance to you are listed here.

1. Role models -- persons to whom you can look as a source of ideas and as examples of what people can accomplish in dealing creatively with difficult situations. They may also provide you with a sense of what kinds of balance you want to build into your life in terms of investments in family members, jobs, community activities, recreation, etc. Role models help to provide a sense of clarity about what the future might look like for you.

2. People in the same boat -- persons who share a common stress or difficulty and with whom you can communicate easily and deeply because they have shared similar circumstances and can identify with your situation. It is pleasant, especially when under stress, to be able to use shorthand or know that others understand what you are up against. Sometimes words are not even needed. Parent-groups, people with a common disability, people in search of answers to a particular problem, and individuals who feel a common fate because of age, sex, race, whatever, are examples of support groups that help people gain perspective on their own situation.

3. Close friends -- although this category is most obvious as an important source of caring and emotional support, it is amazing to find out that there are many folks who simply feel that there are no such persons in their lives. Sometimes this comes about for situational reasons, such as moving to a new community; sometimes it is because people feel they are "different"; and sometimes it is based on reluctance to reach out for fear of being rejected. What is clear is that, regardless of reason, lack of a few close friends can be an important cause of loneliness, anxiety, and withdrawal.

4. Skilled problem solvers -- persons who know how to fix the car, furnace, furniture, or ice box; individuals who seem to know just the right way to bend a coat hanger to unlock the door of the automobile you have locked yourself out of; people who can help with medical problems and transportation difficulties; or those who are willing to pitch in wherever extra hands are needed and know how to do it without needing finely detailed instructions. Sometimes these "experts" are the last persons we would choose to spend free time with, but what they do offer is that first and foremost they are dependable and competent.

5. People who respect you -- these persons are particularly important in helping you maintain your sense of self-esteem and self-worth. They respect your competence at your current level of development and are appreciative of your capacity to carry out tasks and functions regardless of how simple or complex these functions might be. They take you for what you are and value you as you are. Being recognized as a person who is competent in many areas can help you feel comfortable and less devastated by failures in other areas.

6. Information agents -- persons who cannot help directly with a problem you may be having but who know the organization or person who can provide assistance. These are the "librarians" of the support system who can identify resources outside of your immediate contacts and help connect you with them. They know the best baby sitters, ideal spots for vacations, specialized sources of educational or medical talent and programs. They can be a "window to the world" and keep you from being trapped in provincial and local patterns of seeking help.

7. Challengers -- people who are sources of excitement and stimulation and who help you to get out of your rut. At a minimum, they may give you

a guided tour of <u>their</u> ruts; at most, they will inspire you to find a new set of grooves -- alternatives you had not thought possible for yourself. They are often provocative persons and, in fact, sometimes come across as needling you. But if you have built in some of the other kinds of supports listed above, it is often possible to respond creatively to their challenge and devote energy to stretching and developing new skills and competencies within yourself. They sometimes even show you how to learn to like the "heat of the kitchen" through inviting you to master situations which you could only tolerate or withdraw from earlier. Paradoxically, in developing new interpersonal skills, best teachers are often those who seem unbearably pushy.

To help you become clear about <u>your</u> support system, it is helpful to take a large piece of paper and go through the following exercises:

Step 1. Put a symbol in the middle of the paper labeled "ME".

Step 2. Think of individuals, groups, or organizations which you feel are supportive of you

Step 3. In the area closest to you, place the names of those supportive people whom you rely on most and who are most important to you.

Step 4. In the space farther out, place the names of the persons or groups who are important but less central in your life.

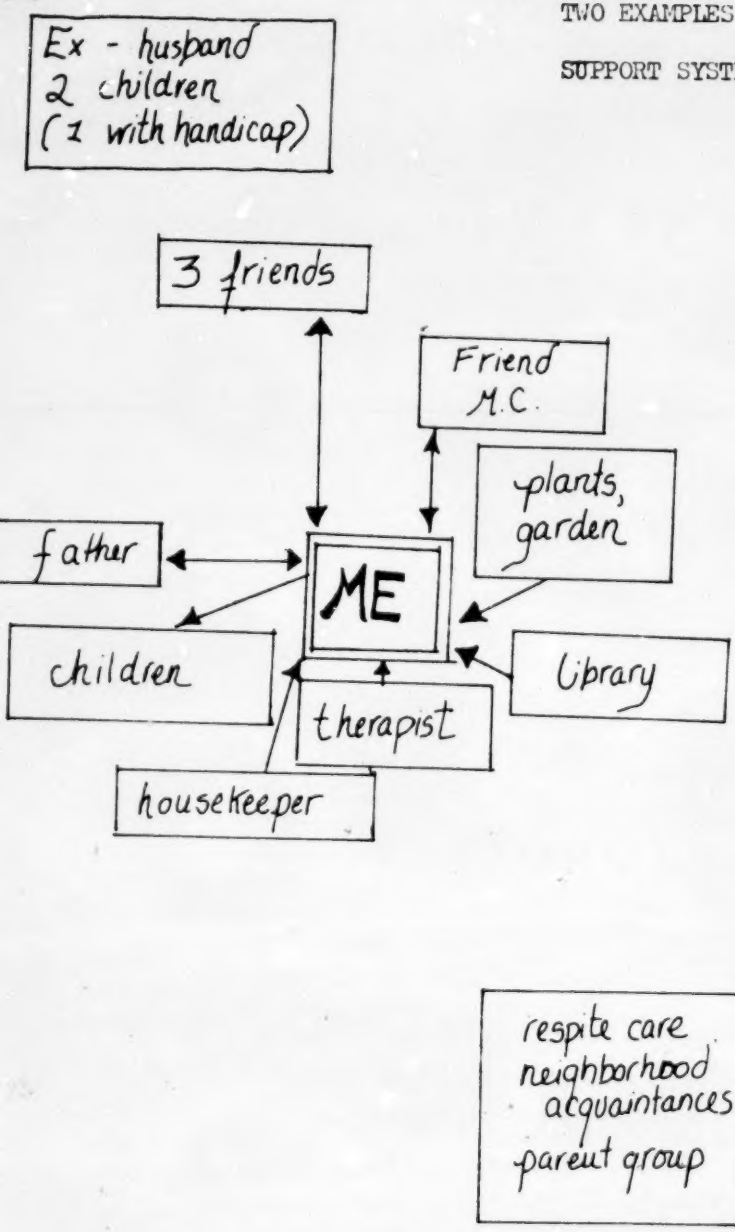
Step 5. In the upper left hand corner, identify thos people who make life most difficult for you, who increase your need for support, or who block you from reaching goals.

Step 6. In the lower right hand corner, list those people who are potential supports to you but whom you never or rarely call on.

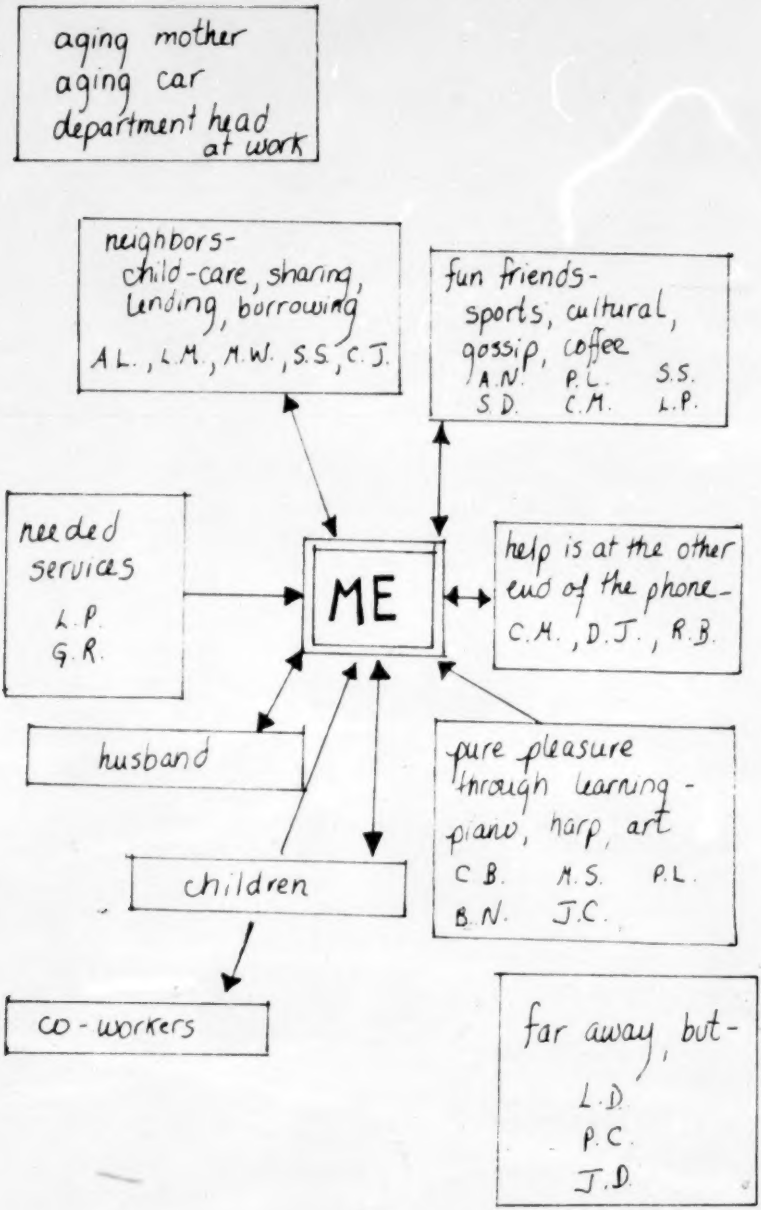
A

TWO EXAMPLES OF

SUPPORT SYSTEMS



B


aging mother
aging car
department head at work
neighbors- child-care, sharing, lending, borrowing
A.L., L.M., M.W., S.S., C.J.
fun friends- sports, cultural, gossip, coffee
A.N. P.L. S.S.
S.D. C.M. L.P.
needed services
L.P.
G.R.
ME
help is at the other end of the phone-
C.M., D.J., R.B.
husband
pure pleasure through learning - piano, harp, art
C.B. M.S. P.L.
B.N. J.C.
children
co-workers
far away, but-
L.D.
P.C.
J.D.

Step 7. You may want to go back and use colored markers and symbols to represent your most important feelings about those whom you have identified.

If you do this in the context of a small group, share and talk about your description of your support system, using the reactions of others to add to, modify, or clarify the nature of the support you need and the support you think is available to you.

ASSESSING YOUR SUPPORT SYSTEM

Diagramming or in some way making explicit to yourself and others the kinds of persons who populate your support system can be a delicate task. It may arouse anxiety to be able to come up with only one or two persons after thinking for twenty minutes. Or it may be overwhelming to notice that all of the individuals are of a particular type and that they merely duplicate each other, while leaving huge gaps in other areas of needed support. Or it may bring about a sense of helplessness or despair to see what is needed but not know where to turn to enrich your support system. There are some typical questions, however, that seem to be helpful when examining the nature of one's system, even if they make you uncomfortable. They include the following:

-- Are there enough people?

-- Do they represent the different kinds of resources I need?

-- Are they available and dependable?

-- What is the cost of asking for their help?

-- Do I feel stronger or weaker when they do help?

-- Can I see the process as a mutual give and take or is it all one way?

-- Are there "saboteurs" in the system who cause me more grief and trouble than they are worth?

-- Do I feel comfortable in asking for help? At what stage of crisis?

-- Can I make my own needs understood easily?

-- Can I tolerate being turned down? or rejected? or let down?

-- Do I know how to motivate and reward individuals who help me?

-- Can I turn to persons who want to help but feel out of my support system?

In assessing your support system, it is critical that there be some reality checks built into the process. It is often helpful to think your system through with other members of your family, or with friends or professional counselors so as to avoid building unrealistically high expectations or, on the other hand, giving up too easily. Experience tells us some of the pitfalls to be on the watch for if we want to build reliable resources into our lives. For instance, it is all too frequent that one parent, traditionally the mother, assumes an unfair share of the burden of providing for the welfare of the other family members.

We know that families acting alone can often fail to bring about the influence and motivation to garner durable and competent sources of help. It is all too frequent that when there is one member of the family in need of a great deal of assistance, the other members give up their own interests and objectives to provide for the more dependent member. This is particularly true of parents, who may find that all of their energy is going into meeting the needs of their children and nothing is left over for their own growth and development of interests outside the family.

When a family is responsible for the long term care of a disabled child or adult, it is possible to get into routines that keep people close to exhaustion and provide for no relief from the care-giving role. If such families are to stay together and function well together, respite care is one necessary support.

WHERE TO CALL FOR INFORMATION
ABOUT RESPITE CARE SERVICES IN YOUR COMMUNITY

Maryland Direction Center (301) 383-6523

Baltimore City and County
Harford County
Carroll County

Central Maryland Direction Center (301) 952-4860

Montgomery County
Prince George's County
Tri-County (Charles, St. Mary's, Calvert)

Eastern Maryland Direction Center (301) 228-1444

Nine counties of Eastern Shore

Western Maryland Direction Center (301) 689-8879

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